
Opening Extract from...

Keeping Mum

Caring for Someone with Dementia

Written by Marianne Talbot

Published by Hay House

Keeping Mum

CARING FOR SOMEONE WITH DEMENTIA

MARIANNE TALBOT

HAY HOUSE
Australia • Canada • Hong Kong • India
South Africa • United Kingdom • United States

First published and distributed in the United Kingdom by:
Hay House UK Ltd, 292B Kensal Rd, London W10 5BE. Tel.: (44) 20 8962 1230; Fax:
(44) 20 8962 1239. www.hayhouse.co.uk

Published and distributed in the United States of America by:
Hay House, Inc., PO Box 5100, Carlsbad, CA 92018-5100. Tel.: (1) 760 431 7695 or
(800) 654 5126; Fax: (1) 760 431 6948 or (800) 650 5115. www.hayhouse.com

Published and distributed in Australia by:
Hay House Australia Ltd, 18/36 Ralph St, Alexandria NSW 2015.
Tel.: (61) 2 9669 4299; Fax: (61) 2 9669 4144. www.hayhouse.com.au

Published and distributed in the Republic of South Africa by:
Hay House SA (Pty), Ltd, PO Box 990, Witkoppen 2068.
Tel./Fax: (27) 11 467 8904. www.hayhouse.co.za

Published and distributed in India by:
Hay House Publishers India, Muskaan Complex, Plot No.3, B-2, Vasant Kunj, New
Delhi – 110 070. Tel.: (91) 11 4176 1620; Fax: (91) 11 4176 1630.
www.hayhouse.co.in

Distributed in Canada by:
Raincoast, 9050 Shaughnessy St, Vancouver, BC V6P 6E5.
Tel.: (1) 604 323 7100; Fax: (1) 604 323 2600

A catalogue record for this book is available from the British Library.

ISBN 978-1-84850-291-8

Printed and bound in Great Britain by
TJ International, Padstow, Cornwall.

MIX
Paper from
responsible sources
FSC® C013056
FSC
www.fsc.org

Contents

About the Author

Marianne Talbot cared for her parents from 1995, when a stroke rendered her father mentally incapable overnight, until 2009 when her mother died, having had Alzheimer's for 10 years. Marianne chronicled the five years her mum lived with her in the popular blog she wrote for *Saga* magazine online. The blog forms the basis of this book.

Marianne worked throughout the time she cared for her parents, as Director of Studies in Philosophy at Oxford University's Department for Continuing Education, where she is in charge of the university's 'outreach' for philosophy, including their very popular online courses.

At 15, however, Marianne was thrown out of school for truancy and disruption. She joined the 'hippie trail', travelling through Iran, Afghanistan, Pakistan and India before spending three years in Australia. She then travelled back through Africa. At 25 she started an Open University foundation course. It was during this she discovered philosophy. She was an undergraduate at the University of London, Bedford College, from 1982 to 1985, after which she moved to Corpus Christi College, Oxford to do graduate work. She taught for Pembroke College, Oxford from 1987 to 1990 and for Brasenose College, Oxford from 1990 to 2000 before taking up her current position in 2001.

From 1996 to 1999, as chair of the National Forum of Values for Education and the Community, Marianne was in charge of the spiritual, moral, social and cultural development of pupils aged 5 to 19 in English schools.

Marianne loves teaching. In 2009 a podcast of one of her lectures, 'A Romp Through the History of Philosophy', became a global number one on iTunes U (the University of iTunes). In 2010 a second podcast, 'The Nature of Argument', also became a global number one. Together they have been downloaded more than 3 million times. Marianne is tickled pink to think that people from all over the world can listen to, and watch, her lectures. You can find them here: http://www.philosophy.ox.ac.uk/podcasts.

In her spare time Marianne likes to keep fit. She cycles, swims and walks. She loves reading, especially detective novels, and the theatre, especially Shakespeare.

Foreword

by Imelda Redmond CBE

CEO Carers UK

I first met Marianne when she, at rather short notice, agreed to appear on stage at a political party Conference in 2009 for a debate on ageing and care. She describes the experience in her own words in this book, but what she doesn't say is just what an impact she had there, and continues to have, as an advocate for carers. As she does in this book, she spoke frankly and powerfully about her experiences of caring, and sent a clear message to that audience – that carers aren't a small group of do-gooders who we can pat on the head and then forget about. Having close friends or relatives who need our care and support can, and will, happen to all of us.

There are six million people in the UK who, in different ways, are living Marianne's story, as they care, unpaid, for elderly or disabled loved ones. Just as ageing is a fact of life, so is caring, and the stark reality is that, with an ageing population, *we will all care* at some point in our lives, or need care ourselves.

Yet our society and our public services have not yet caught up. At Carers UK, our research estimates that carers' contribution is the equivalent of £87 billion each year, but despite this staggering contribution, what carers do is largely unrecognized and undervalued. Our public services would not cope without carers, yet, like Marianne, too many families find that, when they need them, the services are not there to back them up – too inflexible, unreliable or simply not good enough quality. As a result, many carers are caring without the right support and are being pushed to breaking point – forced to give up their jobs, risking ill-health and sometimes poverty. It is time that our society and our politicians listen to the experiences of carers like Marianne, and give carers a better deal.

Part of the problem is that, unless you have lived through caring for a loved one, it is almost impossible to imagine what it is like. Being a carer is to be doctor, nurse, taxi (or ambulance) driver, pharmacist, physiotherapist, counsellor, cook, cleaner, accountant ... the list goes on. But on top of all these tasks and an often grinding battle with bureaucracy, you have to cope with the changes in your closest relationships, loneliness, grief, worry and the loss of your own freedom.

In this book, Marianne tells her and her mum's story, honestly – with all the frustration, despair, satisfaction and joy of being a carer. Her experiences will be a revelation to those who haven't cared for a loved one yet, and will be of huge comfort and help to carers, who will laugh and cry with it all, and know that they are not alone.

Acknowledgements

The word ‘piglet’, used throughout this book for the person being cared for, comes from Hugh Marriott’s wonderful book *The Selfish Pig’s Guide to Caring**. It stands for **P**erson **I** **G**ive **L**ove and **E**ndless **T**herapy to’. I think it conveys just the right combination of love and exasperation. Thank you, Hugh, for letting me use it.

Anita Ljubic, thank you for your unfailing willingness and good humour. Thank you, Andrej, for making Mum so happy, and Sinisa for lending them to me. Thank you also to Carol and Albert.

The wonderful people at the Willows day care know exactly how much I relied on them: a very big thank you. The same to everyone at the special transport service, especially Ray, everyone at Shotover, and everyone at Limes. A special thank you to Marion Collins, our care manager.

The training sessions at the Cowley Road Carers’ Centre were invaluable. Through you I met the wonderful Hubert and Phoebe. Thank you. Everyone at the Headington Care Home was fantastic: thank you Elisa, and all of you for everything you did for Mum (and me). Thank you also to our GP, Gordon Gancz, and to all his brilliant receptionists. You made my life much easier.

---

*Marriott, Hugh, *The Selfish Pig’s Guide to Caring* (Polperro Heritage Press, 2003)

Thank you to everyone in Cheshire who made it possible for Mum to live independently for so long. Lynne, Anita and Christine, thank you. John and Rosemary, Gordon and Elvina, Jean and John and all Mum's other Poynton friends, thank you.

Thank you to my colleagues at Oxford University's Department of Continuing Education and TALL. A special thank you to Philip Healy. Many thanks to members of the OUDCE Philosophical Society, especially committee members past and present.

Without the people at *Saga* this book wouldn't have happened. Thank you especially to Melody, Andy, Chris, Emma, Katy and all the readers of the blog (especially Bill!).

Joanna Foster, Felicity, Ian, Ollie and Rob Steadman, Philippa Morrison, Susan Quilliam, Joelle Mann and John Shirley: how often you made everything possible. Thank you for your friendship, and for opening your arms to Mum.

Finally, there's my family. In particular, Ian and Betty. Thank you. You were absolute rocks. Christopher, Judy and Richard: thanking you doesn't seem right; Mum, after all, was your mum too, she adored us all, and would, I'm sure, be proud of us for the way we managed her final years. I hope that if you read this you will recognize Mum and, if reading it prompts tears, that they are tears of happiness.

– *Marianne Talbot*
December 2010

Introduction

In late 2006, life was full. I was a trustee of the Girls' Day School Trust, I was Director of Studies in Philosophy at Oxford University's Department for Continuing Education, I was writing *An Introduction to Bioethics for Scientists* for Cambridge University Press, and I was Tawny Owl for a local Brownie Pack.

I was also caring for Mum.

Mum was then 86. In 1999 she had been diagnosed with Alzheimer's. She came to live with me in 2003. At first life was relatively easy. Mum could be left alone. She could also be taken out. She'd come to my lectures, to friends' dinner and lunch parties, and she loved going to the cinema, the theatre and the opera.

She was also able to help in the house (though 'help' was not always how I thought of it!). We went shopping and did the housework together, the ironing basket was empty, the silver shone and the garden had never looked better. Life was good. It was a darn sight better than it had been caring for her from a distance: what a recipe for anxiety, guilt and worry *that* had been.

By 2006, though, this happy situation was long over. I still occasionally left her alone. But I was plagued by guilt and worry. She could still come out with me. But I spent my whole time watching her. She still came to my lectures. But this was entirely thanks to my wonderful students; particularly members of the Philosophical Society.

At home, life was fraught. Social Services had become involved. Mum was going to day care. The house was never my own. It was increasingly difficult to keep the balls in the air.

It was at this point I added to my ‘to do’ list a monthly blog for *Saga* magazine online. Was I mad?

No. The blog added to my ridiculous workload, but writing it was incredibly therapeutic.

If I was stressed, anxious or angry, I expressed it in the blog. If I was sad, depressed or worried, writing the blog was comforting. If something funny happened, or my love for Mum felt particularly strong, into the blog it would go. If I had had a run-in with a jobsworth, where better to vent my fury than to the blog?

To my huge pleasure the readers – mostly other carers – lapped it up. Very soon the web-editor, Melody, asked me if I would do a weekly rather than a monthly blog. I was happy to do so. I derived huge comfort from the messages left by other carers, especially those saying they found the blog helpful.

It was like having a group of supportive friends in whom to confide. Friends, furthermore, who I knew would understand. It is only if you have cared for someone with dementia that you can really understand what it is like. Others sympathize, understand intellectually, commiserate and tell you you’re doing a great job. But they do not understand the visceral fear, anxiety, loneliness and fury that are part and parcel of being responsible for someone whose mind is fragmenting.

Nor do they understand the logistical nightmare of dealing day in, day out with someone whose memory span is literally 3 seconds long.

People often think that caring for someone with dementia must be like caring for a child. This comparison is misleading. Extremely misleading.

A child who is able to walk is cognitively streets ahead of someone whose dementia has reached the final stage. A friend of mine once – very kindly – visited Mum with his two small dogs. Mum, adoring animals, was delighted.

My marvellous friend, despite knowing Mum had end-stage Alzheimer's, couldn't wrap his mind around the fact that, as the dogs disappeared behind the sofa, they ceased to exist for her. He described to me in wonder how, every time they reappeared, her delight was as if she had no idea they were there. This, of course, was exactly the situation: she didn't have any idea they *were* there when she could no longer *see* them there.

The human memory is extraordinary. If it works it goes unnoticed. The temporary loss of a particular word or name is momentarily frustrating, and as we get older memory lapses become more frequent. But normal age-related memory loss is as nothing compared to the profound loss that comes with dementia.

Imagine not being able to hold a conversation (you can't remember the last thing said). Imagine not being able to learn anything new (including the location of the loo in your own home). Imagine not being able to remember the names of your children, or how many children you have. Imagine not knowing where you are, why you are there or who anyone else is. Imagine not knowing who *you* are.

Imagine all this and thank God for your memory.

Our identities, our very sense of who we are, are spun from a web of memories: memories we share with siblings, partners, children and friends, memories of what we have felt and believed at different times of our lives, memories of things we are proud of and things that make us blush with shame. If we lose our memories there is a deep and profound sense in which we lose ourselves.

If you are caring, or have cared, for someone with dementia, this will be familiar to you. You will know the desperate sadness of watching someone you love descend into this pit, a pit in which they are isolated from any, and every, other human being. Even from you.

But you will also know that the stripping away of a person's memory is *not* the disintegration of the whole person. Something is left.

Until the day of her death, Mum was still *Mum*. She had no idea who I was, but her eyes lit up when she saw me. She couldn't produce a meaningful sentence, but she still understood – and loved – a bear hug. She would eat the daffodils I gave her for Mother's Day, but her enjoyment of food was intact.

I am proud of having brought Mum to live with me for her final years. Caring for her leaves me a legacy of love that will last until the final years of *my* life. When she died I felt I had done everything I could to make the end of her life as comfortable, and meaningful, as possible.

If you are a carer, this is what you are doing. It is, I believe, one of the most important ways someone can spend their time. You are doing everything you can to make the most of the life of another human being.

Amazingly, when you put 'carer' on your CV it won't impress anyone. In our society people are more impressed by your pay packet than your willingness to care for someone you love. But you know and I know that this, really, is where it is at. Be proud.

Now the blog has become – with the help of the wonderful people at Hay House – this book. In it you will find some new blogs and, at the end of each blog, a short tip or commentary. I have included my popular short piece for *Saga* magazine 'Marianne's Tips for Carers'. There are also short chapters on the practicalities of, firstly, money, property and the law, and secondly Social Services, health and welfare. With some trepidation, I have included a short chapter on 'Carers' Fury': you will know what I mean. There are also lists of addresses you might find useful.

I should be very happy if the practical suggestions in this book make life easier for you. I should cringe, though, if you thought that in offering such tips I am setting myself up as an expert carer. All I can justifiably claim to be, after 14 years, is an *experienced* carer. One with friends who are also experienced carers and who have been happy to share with me tips that they have found useful. I pass these tips on to you hoping they will help.

Both my beloved parents, having lived long, productive and enjoyable lives, are now dead. My caring duties are over. Many of you are not in this position. Some of you – caring for partners or children – may never be in this position. I feel for you from the bottom of my heart.

But I know that you won't begrudge me my freedom. I promise you I'll use it well. I also promise I shan't forget you. I shall do everything in my power to promote the cause of carers: if I can help *you,* or an organization you belong to, be in touch at the address below or on the Keeping Mum website www.keepingmum.org.uk

Marianne Talbot
c/o Hay House
marianne.talbot@conted.ox.ac.uk